# THE EXPERIENCES OF FAMILY MEMBERS DURING THE CRITICAL ILLNESS OF A LOVED ONE ADMITTED TO AN INTENSIVE CARE UNIT

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#### ABSTRACT

Family members with a loved one in the intensive care unit are faced with a large amount of stress and anxiety invoked by the admission to the unit known for its high mortality rate. This influences the physical and mental health of family members and often overwhelms the family's coping abilities. The objective of the study was to explore the experiences of family members during critical illness. Using a grounded theory approach, a total of nine family members participated in the study. In-depth individual interviews were used to collect data with sampling starting off with convenience sampling, which progressed to theoretical sampling. Data analysis included open and axial coding. Family members' experiences were categorised as emotional turmoil, interrupted physical functioning and stress and crisis. Although the findings of this study were confined to the province of KwaZulu-Natal in South Africa and are not generalisable for the whole population of family members with a loved one in an intensive care unit, the similarities in the experiences are consistent with the experiences of studies done internationally. This study reiterates that a critical illness is indeed a stressful event in the lives of family members. This study recommends that more family research is needed in the discipline of critical care

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Africa Journal of Nursing and Midwifery Volume 19 | Number 1 | 2017 | pp. 56–68 https://upjournals.co.za/index.php/AJNM/index https://doi.org/10.25159/2520-5293/1446 ISSN 2520-5293 (Online), ISSN 1682-5055 (Print) © Unisa Press 2017 to find ways to improve the care provided to family members. In addition critical care nurses should be aware of the importance of conducting a family needs assessment during the care of the critically ill patient.

Keywords: critical illness, family experiences, family stress, intensive care

### INTRODUCTION AND BACKGROUND INFORMATION

Family members (FMs) with a relative in the intensive care unit (ICU) are faced with an emotionally upsetting crisis period due to the stress and anxiety invoked by the admission to the unit known for its high mortality rate. Admission to an ICU is mostly unplanned and the patients are almost deemed to be in a critical condition (Hashim & Hussin, 2012:13). Admissions to ICU are often due to life-threatening illnesses resulting from trauma, surgery, sepsis or shock where patients are susceptible to dysfunction of multiple organ systems including respiratory, cardiovascular and digestive systems (Wright-Myrie, Khawa & Dover-Roberts, 2013:49). This event results in symptoms of depression and post-traumatic stress disorders, anxieties surrounding the illness, fear, disbelief, and uncertainty about the prognosis influencing the physical and mental health of FMs. It often overwhelms the family's coping abilities (Nelms &, Eggenberger, 2010:462).

McAdam and Puntillo (2009: 205) state that more than 50% of FMs who experience the critical illness of a loved one report symptoms of depression, hypochondria, suicidal depression, low energy depression and anxious depression. Acute stress experienced by FMs in ICUs is so significant that it can be compared with patients suffering from post-traumatic stress disorder in a psychiatric unit. According to Pochard, Darmon, Fassier *et al.* (2005:91), anxiety and depression were extremely common (69.1% and 35.4%, respectively) among FMs visiting patients in ICU. Symtpoms of either anxiety or depression were found in 72.7% of FMs and 84% of spouses.

Any conflict or stressor that arises can threaten optimal family functioning and can throw the family unit into a state of disequilibrium or even cause a crisis. When a loved one is expectedly or unexpectedly admitted to intensive care, FMs may be caught off guard, resulting in disorganised and disruptive terms of functioning within the family and as individuals because, in such circumstances, the demands made upon them may exceed their capabilities (Pryzby, 2005:20).

### STATEMENT OF THE RESEARCH PROBLEM

Amidst the advanced technology, and the fast paced environment of the ICU, FMs often play a significant role in promoting the psychological wellbeing of the critically ill patient through their familiar caring and presence. Despite this, FMs' ability to support the patient may become compromised (Bailey, Sabbagh &

Loiselle, 2010:115). The ICU is one of the places in the hospital where more is required from FMs than any other area of health care, as they are often requested to represent the patients who are too ill to make decisions or communicate their wishes. However, the psychological turmoil experienced by FMs may serve as obstacles in FMs effectively representing the patient affecting the patient's length of stay in ICU or quality of life (Pochard, Darmon, Fassier *et al.*, 2005:91).

There have been extensive studies reporting the needs of FMs (Daley, 1984:231; Davis-Martin, 1994:515; Bailey *et al.*, 2010:143; Cypress, 2011:273). One such landmark study was by Molter in 1979, which used a 45-item questionnaire surveying the needs of FMs. This questionnaire has since been the guiding instrument for further studies of FMs' needs in the ICU ((Hashim & Hussin, 2012:12). There have also been many studies exploring the symptoms experienced by FMs during the critical illness of a loved one in the ICU (Ågård & Harder, 2007:170; Kinrade, Jackson & Tomnay 2009:83; Karlson, Forsberg & Bergbom, 2010:93). While there have been many reported studies conducted in western societies, there have been very few reported studies conducted in the African context, especially in South Africa.

According to Saloojee, Rosenbaum, Westaway and Stewart (2009a:23), there is limited family-centred care research within the South African context and more specifically resource constraints settings. This was also documented by Irlam and Bruce (2002:28) who conducted family-centred care studies in a pediatric context and suggested that family-centred care models of care be developed for the pediatric setting with emphasis on the participation of parents. This article reports on family members' experiences during the critical illness of a loved one and forms part of a larger study that aimed at developing a theory towards providing care for families during this critical time. Providing care to FMs within an ICU context should be tailored to what the FMs actually need and not what health professionals believe they need. The most appropriate way to obtain this information was to ask the families themselves.

## PURPOSE OF THE STUDY

The purpose of the study was to explore the experiences of FMs who have a loved one admitted to an ICU following a critical illness.

### **RESEARCH METHODOLOGY**

A qualitative method following the grounded theory approach (Strauss & Corbin, 1990:20) was used. This method was chosen as there is a limited research in the area of family care in the context of South Africa and grounded theory is best suited in areas where there is limited research.

Six ICUs of two hospitals were used, one public hospital and the other a private facility. The private hospital was a Level 1 facility with 400 beds and the public

a Level 2 hospital with 807 beds. These hospitals were chosen because they were accessible to the researcher.

The FMs of patients admitted to the ICUs participated in the study. FMs included the spouse, parent or children (18 years of age or older). An FM also included a person who played a significant role in the patient's life with no legal relations. Sampling began with convenience sampling where the researcher began by including participants who were readily available. As the data was analysed using the coding method characteristic in grounded theory, relevant codes emerged. Hence the researcher moved from convenience sampling to theoretical sampling. A total of nine FMs were interviewed as data saturation was reached at this point as no new or relevant data seem to emerge regarding a code. Four FMs were used during convenience sampling and five FMs were used during theoretical sampling.

Data collection commenced immediately after ethical approval was obtained from the University of KwaZulu-Natal's ethics committee with ethical approval number HSS/0102/10. In addition the necessary permission from the management of both hospitals was also obtained. The unit managers were then contacted telephonically to set up appointments within the units with the purpose of informing the unit managers about the aim of the study and setting convenient times for data collection within the units. Once the data collection time was negotiated, the researcher put up signs in the respective units inviting FMs to participate in the study. Data collection occurred between August and November 2012. One hour in-depth semi-structured interviews were conducted in English. The interviews were audio recorded with the permission of FMs and then transcribed verbatim. FMs were interviewed in places that were convenient for them, such as the waiting area of the critical care units, hospital coffee shop and the critical care coffee lounge.

Data collection and analysis occurred simultaneously and included the process of open coding that included identifying words, lines, segments and incidents of the data yielding the experiences of FMs. Categories and subcategories were then developed from the data, focusing on their properties and dimensions. Axial coding followed open coding that included relating categories to subcategories.

Credibility was ensured by peer debriefing for external validation. Dependability was ensured by a dependability audit, where the researcher used an expert intensive care nurse to review the audio tapes and written transcripts so as to validate the findings. A confirmability trail was also established by recording the research activities over time so that others can follow the research process undertaken. Transferability was ensured by providing a thick description of the research setting so as to allow for others to evaluate the applicability of the data in other settings.

After receiving ethical approval from the University of KwaZulu-Natal's Ethics Committee, permission was also sought from the Department of Health in KwaZulu-Natal. All participants were presented with a written information document explaining the purpose and significance of the study and written consent was obtained. Participants were made aware that participation was voluntary and that withdrawal from the study could happen at any time. Permission to audio record the interviews was also obtained from all participants. Anonymity was maintained by not linking any names to any participants, and data obtained was treated confidentially and could not be traced to individuals. As the data collected was of a sensitive nature, the researcher ensured that a psychologist or social worker was available should the participants require debriefing. At times the researcher required debriefing, as the nature of the data obtained was emotionally challenging.

### THE FINDINGS

The following table provides a brief description of the FMs who participated in the study.

FM	Age	Sex	Cultural group	Relationship to patient	Patient age and diagnosis	Time ventilated	Patient outcome
1	Early 60s	F	Hindu	Wife	65 years, peripheral vascular surgery	60 days	discharged
2	Middle 40s	F	Christian	Wife	55 years, poly trauma	7 days	deceased
3	Late 30s	F	Hindu	Mother	10 years, ENT surgery	14 days	deceased
4	Early 40s	F	Christian	Daughter	70 years, Myocardial infarction,	14 days	discharged
5	Middle 50s	F	Christian	Wife	60 years, head injury,	13 days	deceased
6	Middle 30s	F	Christian	Wife	40 years, Motor vehicle accident	14 days	transferred
7	Late 40s	F	Christian	Daughter	55 years, Motor vehicle crash	5 days	deceased
8	Early 30s	F	Hindu	Sister	25 years, motor vehicle crash	21 days	transferred
9	Late 30s	М	Christian	Husband	32 years, eclampsia, caesarian section	4 days	Transferred, baby deceased at birth

 Table 1:
 Profile of family members

Family members' experiences were categorised as emotional turmoil, interrupted physical functioning and stress and crisis within the family unit.

### Emotional turmoil

It became clear from the results that the sudden illness and the unexpected admission of a loved one to an ICU are experienced as a catastrophic event for FMs. They explained that they had found themselves being 'caught off guard' and had experienced shock as they were psychologically unprepared for sudden critical illness and the ICU setting. They were unable to comprehend what was happening and felt overwhelmed, confused and vulnerable:

What I couldn't understand [was] that a normal child walked in for a procedure that was just like a day procedure and next thing my child is lying in ICU on a ventilator, it was like I was gone blind, I did not know what was happening to me, you know I was like shocked (FM 3, mother).

It was really shocking because on the day of his [the patient's] admission, I did not know that he was going to have a big operation, I think that he also was not expecting this and it was really shocking ... it was very traumatic for us, for me and my children too, we didn't expect this, it was really confusing (FM 1, wife).

Seeing the patient in the technical milieu of the ICU was also unexpected and frightening for FMs. FMs said that they did not fully comprehend the seriousness of the situation until they noticed that the patient was connected to strange tubes, life support and surrounded by machinery and alarms:

I didn't realize how ill she was, until I saw her in the ICU. Initially I thought it was just her blood pressure that was the problem, I only realised that she was really ill when I saw her on the life support machine (FM 9, husband).

Mom had like four or five machines, and she had all these tubes, and I did not know what was going on .... I was standing there and my mom was getting agitated and the buzzers were going off all the time. I thought, okay, what I am doing wrong (FM 4, daughter).

The participants also highlighted that this changed the familiar personality of the patient to that previously known, sedated, unconscious and unable to communicate. The crumbling of the former image of the patient was in most instances unanticipated, shocking and emotionally challenging:

He was unconsciousness and we didn't know whether we was able to speak to him, we were not sure whether he was sedated or whether he was just unconscious. He had blood all over him (FM 8, sister).

I could not believe that this was him on the bed because he was an active person, and he was just lying there, helpless and people were helping him, doing stuff for him, and that was very unexpected and scary, I could not believe it (FM 2, wife).

My thoughts were you know seeing a normal child walk into the hospital and then seeing your child like this with all this tubes all over him and err just lying there so lifeless; I didn't even know how I felt, everything was just a shock to us (FM 3, mother).

It also emerged that health care professionals were perceived as exercising their authority over FMs by not allowing them to be physically close to the patient, even when the patient was on the brink of dying. This resulted in feelings of anger, frustration and injustice. Some FMs suggested that if they had been granted the opportunity to engage in a supportive role with the patient, their proximity might have had a therapeutic value and their loved one would have had a better chance of recovery:

[S]he [the intensive care nurse] basically chased me away ... hmm ... which I felt at that time was very wrong because to me ICU is, if you not causing the patient any more distress or anything like that, I don't think that you should be stopped ... you don't know how much time you are going to have left with him, and who wants to see him for an hour a day, may be if you can let me get talking to him a little, help him come out this for whatever that he is in (FM 5, wife).

FMs experienced 'alterations in their perceptions of time'. The uncertainty of not knowing what the outcome would be for the patient resulted in them living in a state of suspension. They explained that when the patient's condition had been unstable, they had lived one day at a time and that every day had been different, with days alternating between hope and despair:

I could not imagine my life without my wife, and waiting to find out whether she would survive was very hard to do. I had to take each day as it came, as she was very ill. Some days her BP would be slightly lowered and other days it [would be] even higher. Some days I had hope and the other days I was scared (FM 9, husband).

FMs found the unpredictability of the situation arduous and became apprehensive about the short and long-term effects of the illness for the patient:

The anesthetist came and told me that he thinks that she is going to have kidney problems and that she might have brain damage, so that made me scared (FM 4, daughter).

He takes disprin to thin his blood he [doctor] explained that the bleeding was going to affect his speech (FM 6, wife).

The doctor explained that the heart is not working: the lungs are not working ... they told us that the kidneys are also not working, so we are worried now (FM 7, daughter).

FMs could not foresee their lives without their loved one and the uncertainty about the outcome resulted in FMs not being able to plan a future with or without the patient:

I could not imagine my life without my wife, and waiting to find out whether she would survive was very hard to do. I could not imagine what would happen without my wife (FM 9, husband).

Some FMs recounted that they felt isolated when HCP ignored them. FMs explained that they were willing to participate in care, but that this was not acknowledged and attempts to contribute to the patient's recovery were deliberately ignored.

The nurses were like screaming and yelling and talking and they were not interested in talking to us. They ignored us even though we were willing to help. They were talking to each other, we wanted to know what they were saying, because they were talking in Zulu and we were not sure as to whether they were talking about us or the patient (FM 8, sister).

...you know when a parent tells you something is wrong with their child, I feel they should have went an extra mile and looked into it, not just tell me that it's a normal thing you know ... if the child's is white as the sheet there is something wrong, look into it (FM 3, mother).

### Interrupted physical functioning

FMs reported that their normal physical functioning became disrupted as a result of the sudden illness of a loved one. Many reported changes in patterns of eating, drinking, sleeping and attendance at work. The constant need to be close to the patient resulted in many FMs experiencing a sense of being immobilised, with a resultant neglect of themselves, as they felt that the needs of the patient took precedence over their own. FMs also reported the stress of the patient's admission had lowered their appetite for food. They were unable to sleep, as they were preoccupied with issues related to the patient. Many hours were lost as FMs spent nights in the waiting room of the ICU. Not eating or drinking placed FMs at risk and caused them to feel exhausted. The new rhythm of their lives was dictated by visits to the patient, leaving little time for them to think of themselves. Non-attendance at work placed a financial burden on some of the families:

I couldn't do anything, we sat at the hospital the whole time until the operation was over and they brought him out of theatre. Everything was altered, I didn't go to work, I didn't go to work for two to three days, I just sat with my aunt the whole time, we were not eating properly, we were feeling very depressed so there was not a chance of eating. We were at the hospital for many hours with no sleep, we were tired, we were exhausted because we kept on, and we did not leave the hospital (FM 7, daughter).

I did not sleep, I did not eat ... I could not do anything but just sit and wait for any news about my husband ... you forget about yourself in times like this .... I had FMs calling me and asking me whether I ate or not ... you can't in a time like this (FM 6, wife).

I spent most of my time at the hospital .... I did not go to work .... I am the only one working and as a result my finances were affected ... my wife was unemployed during the time of her pregnancy so I was the sole earner at home ... when I lost my baby and my wife was admitted in ICU ... I could not function as I normally did (FM, husband).

Ok this one is much better ... this code is more to the point and just has a few important quotes which illustrate what you were saying very well ... make the others like this one (FM).

### Stress and crisis within the family unit

The emotional turmoil and interrupted physical functioning of FMs, in response to the critical illness of a loved one, lead to extreme stress. The physical response of stress was perceived to be threatening to the normal homeostasis of individual FMs. The patient's sudden illness imposed strains that exceeded their resources and normal coping mechanisms. These stressors were characteristic of a crisis among individual FMs as well as in the family as a whole:

I think the patient is part of the family, I think he/she [FM] is an extension of the family .... It creates a crisis for FM, emotionally or psychological, even physically, it creates a crisis (FM 9, husband).

Oh yes, definitely your emotions, your physical wellbeing everything is in crisis because, it does not affect the patient, but also you as a FM. You feel challenged and feel like you can't cope (FM 8, sister).

The stress in the family unit resulted in disruptions, such as FMs not being able to fulfill their usual family roles. They suffered decreased performance in their family roles and even had to change their usual roles to accommodate to the new situation:

Admission to an ICU is definitely a crisis .... It's disturbing for us and it affects our normal functioning and roles. Some of us are totally lost and they cannot function (FM 8, sister).

### **DISCUSSION OF FINDINGS**

#### **Emotional turmoil**

According to Bowden and Greenberg (2010:19), hospitalisation leads to family disequilibrium where family members cannot adjust by using their repertoires of capabilities in relation to this stressful event. Murgatroyd and Woolfe (1982:70) also reiterate that a sudden situational crisis, such as hospitalisation, affects all FMs at different stages of their lives. This was supported by Plakas, Cant and Taket (2009:15), who found that intense emotions were profound among FMs during the hospitalisation of a loved one to the ICU. Emotions were characterised by fear, agony, anxiety, crying and feelings of pain and uncertainty. The findings of Bailey, Sabbagh, Loiselle, Boileau and McVey (2010:118) revealed that FMs experience extreme psychological distress characterised by anxiety, depression and even signs of post-traumatic stress disorder.

FMs frequently expressed the emotional challenge of seeing the changed and helpless state of the patient. Seeing the patient in the technical milieu of ICU connected to tubes and machines was described as shocking and frightening, instilling feelings of helplessness. McKieran and McCarthy (2010:255) reported that FMs experienced an initial shock at seeing a loved one in the ICU. FMs expressed a sense of unreality and confusion at seeing their relative in the ICU and described their feelings at seeing the critical ill patient with tubes and mechanically ventilated as frightening and unreal. According to Plakas *et al.* (2009:15), the changed identity of the patient due to changes in appearances and decreased level of consciousness meant that FMs could not 'find the person they used to know'. These authors described this as an 'emotional intimacy' that was lost. Engstrom, Uusitalo and Engstrom (2011:7) revealed that some FMs reported feeling afraid and unsafe in the unfamiliar environment of the ICU, which made them keep a distance from the patient. They also found it difficult to be near the patient in instances where it was hard to recognise the patient due to swelling, sedation and intubation.

#### Interrupted physical functioning

The findings of this study indicate that FMs who suddenly had to face the stressful, critical illness of a loved one experience a change in their normal patterns of eating, sleeping and attending work. FMs become unable to carry out their normal daily duties as their whole existence becomes focused on the patient. Figley (1989:42) reported that when families are traumatised and their normal homeostatic mechanisms are disrupted, it results in lowered performance in their usual life routines and roles, resulting in physical symptoms. This is in accordance with Lee and Ling Lau's (2003:493) study, where sleep deprivation and fatigue were common problems that put FMs at risk for developing physical illness, decreased attentiveness, irritability and compromised decision making ability. Chan and Twinn (2006:186) found that participants in their study experienced a change in role and responsibilities that affected their ability to function physically. In the study conducted by Engström and Söderberg (2004:300), participants reported that their daily duties became unimportant following the critical illness of a loved one. Spouses of critically ill patients said that they had not slept at all for the first few nights following the ICU admission as they had not felt the need to sleep. Other participants reported that they had slept fitfully in case there was a telephone call from the hospital. These authors added that participants felt they had to force themselves to do errands and daily chores.

Sarajärvi, Haapamäki and Paavilanen (2006:204) found in their study that many FMs suffered from physical reactions such as sleeplessness (31%), headaches (28%), lack of appetite (16%), stomach ache (9%), tachycardia (7%), and nausea (5%). FMs who have little time to rest are at risk for personal health problems, which threatens their adaption to the situation. This has an impact on the decision making required

by FMs on the part of the patient and may ultimately impact the recovery of the patient (Söderström *et al.*, 2009:253). FMs also suffer physical strain such as fatigue and exhaustion caused by long hours spent at the hospital or travelling between home and the hospital. This leaves them feeling 'tired and worn out' and some FMs reported that the ICU environment adds to the discomfort because there is nowhere to rest and no access food and drink (Nelms & Eggenberger, 2010:470).

### Stress and crisis within the family

The findings of this study suggest that the stress and crisis experienced by FMs exceeded their normal coping mechanisms, resulting in disruptions in family life and leaving FMs feeling disempowered as they felt that they did not have control over their lives or that of the patient. In addition to this, the critical illness did not only affect the patient, but also other members of the family as FMs were seen as being interconnected with one another. According to Minuchin, Rosman and Baker (1978:30), the family grows, changes, reproduces and is a series of interrelated parts. Dysfunction or illness is defined as the closing down of the family system, much the same way as closing down the circulatory system is dysfunctional for the whole body.

Hall and Weaver (1974: 65) stated that each FM has a part to play, assigned to him/her by the family and these given roles have the potential for emotional health or illness. When a crisis is experienced, some FMs may not be able to carry out these roles. Critical illness causes distress and anguish for FMs, which can cause a crisis within a tightly interwoven family. The social role of the patient as a comforter, organiser, mediator, lover, friend or disciplinarian becomes absent within the family unit and, in some instances, FMs have to take on one or more of these roles within the family.

## CONCLUSION

The similarities in the experiences of FMs in this study are consistent with the experiences of studies done internationally. This study reiterates that a sudden critical illness is indeed a stressful event in the lives of FMs and results in disorganisation and disruption of individual roles within the family unit.

## LIMITATIONS

The study was conducted in only an urban setting and in one province of South Africa. This study could have gained from the experiences of FMs if other provinces were included. FMs were also interviewed within the context of ICU during the admission of their loved one, which could have been difficult for them to adequately express their experiences as they could have been distracted by the admission. In

addition to this, I, as a CCN (critical care nurse) myself, completed the interviews with FMs. This could have had restrictions on the information shared by FMs as they could have led to some discomfort knowing that I am a CCN.

### RECOMMENDATIONS

The aim of the study was to facilitate an understanding of the experiences of FMs during the critical illness of a loved one. Results of this study provide awareness and knowledge of these experiences to critical care nurses. Knowledge and awareness of these experiences of family members could be used by health care professionals to provide care that is focused to the FMs; however, this is a building process to be achieved over time. This could be achieved by more research focusing on FMs of critically ill patients, within the South African context, with the hope of guiding health care professional to provide the best possible care to FMs. The critical care context should also consider including a family needs assessment as part of the patient assessment.

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